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Disclaimer

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Presenter Disclosures

- Roseanne D. Dobkin, PhD
- The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:
  - Grant funding from the National Institutes of Health and the Patterson Trust Awards Program in Clinical Research
Objectives

- To provide a brief overview of the non-motor/psychiatric complications that are frequently experienced by people with Ataxia.

- To discuss the applications of Cognitive-Behavioral Therapy (CBT) to the treatment of depression and anxiety in Ataxia.

- To present preliminary data on the use of Cognitive-Behavioral Therapy for treating the depression and anxiety that commonly co-occur with Movement Disorders.
Non-motor or Psychiatric Symptoms in Movement Disorders

- Depression
- Anxiety
- Sleep
- Fatigue
- Psychosis
- Impulse Control Disorders
- Cognitive Changes
Non-motor or Psychiatric Symptoms in Movement Disorders

- Very common
  - Affect the majority of those diagnosed
  - Prevalence rates in Ataxia range from 20-75%
- Major impact on functioning
  - Faster rate of physical and cognitive decline
  - Greater decrements in self-care
  - Negatively affects quality of life/relationships
- Under-diagnosed
- Sub-optimally treated
Non-motor or Psychiatric Symptoms in Movement Disorders

The Good News!!!!

▸ APSECTS OF THE MEDICAL CONDITION OVER WHICH YOU HAVE CONTROL

▸ NO CHOICE IN THE DIAGNOSIS

▸ EVERY CHOICE IN THE COPING RESPONSE
Cognitive-Behavioral Therapy

- Evidence-based psychotherapy with substantial empirical support in other populations

- Targets *thoughts* and *behaviors* related to the onset and maintenance of depression and anxiety

- Very suitable for addressing psychiatric concerns in Ataxia
Key Points of Emphasis

- **Structured and active approach**
  - Homework and practice

- **Concrete coping skills**
  - Breathing and relaxation training
  - Goal-setting
  - “Acting According to Goals” (not feelings)
  - Thought monitoring and restructuring

- **Amenable to family involvement**
  - Facilitate practice of new coping skills at home
Key Points of Emphasis

- **Multiple techniques/modules**
  - Target psychiatric complexities
  - Individualized, tailored approach

- **Illness-related beliefs/themes**
  - Cognitive techniques
  - Power of REALISTIC THINKING

- **Mood and motor function**
Key Points of Emphasis

- Multiple interacting causal factors
Examples of 1:1 Patient Interventions

- Increasing meaningful and social activities
  - Old
  - New
  - Modified
- EXERCISE !!!!!!!
- Problem solving for physical limitations
  - Follow through with referrals for PT, OT, and Speech
  - Experiment with assistive devices as needed
  - Pacing of activities
  - Appropriate daily goals/ less rigid demands
Examples of 1:1 Patient Interventions

▶ Anxiety management and relaxation
  ▪ Breathing exercises
  ▪ Progressive muscle relaxation
  ▪ Guided visualization
  ▪ Worry control

▶ Sleep hygiene
  ▪ Using bed for sleep only - not TV, paying bills etc.
  ▪ Relaxing before bedtime
  ▪ Keeping regular sleep hours
  ▪ Limiting excess time in bed, daytime naps, caffeine, or alcohol in the evening
Examples of 1:1 Patient Interventions

- Thought monitoring and restructuring
  - Rethink the big picture
    - Catch the negative thought
    - Press pause
    - Rewind
    - Replay
  - Multiple methods/techniques
<table>
<thead>
<tr>
<th>Situation</th>
<th>Emotion</th>
<th>Thought</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newly diagnosed with Ataxia</td>
<td>Hopeless</td>
<td>My life is ruined.</td>
</tr>
<tr>
<td></td>
<td>OR</td>
<td>I have no control.</td>
</tr>
<tr>
<td></td>
<td>More/less hopeful</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxious</td>
<td>I wish this didn’t.</td>
</tr>
<tr>
<td></td>
<td>Scared</td>
<td>It will be horrible if I have symptoms in public.</td>
</tr>
</tbody>
</table>
Red Flag Thinking Patterns

- **Mindreading**: “My symptoms make my friends uncomfortable.”
- **Fortunetelling**: “I won’t enjoy the ball game.”
- **Labeling**: “I am useless.”
- **Unfair Comparisons**: “I can’t work as efficiently as I used to, so my contributions are insignificant.”
- **What If**: “What if I am unable to speak at the fundraiser?”
- **Catastrophizing**: “I can’t handle this.”
- **Emotional Reasoning**: “I feel anxious so I need...”
Red Flag Thinking Patterns

- Overgeneralizing: “Everybody in the restaurant is staring at me.”

- Shoulds: “I should be able to concentrate, and if I can’t, I am a failure.”

- All or Nothing Thinking: “The seminar was a complete waste of time.”

- Blaming: “I can’t exercise because I have Ataxia.”

- Personalizing: “My spouse was grumpy last night because my condition is too much for her to handle.”

- Discounting the Positive: “Exciting Ataxia research is being funded, but that doesn’t matter since there is still no cure.”
“Evidence For and Against”

- **Automatic Thought:** “I am helpless.”

- **Evidence For:** I have a progressive neurological disorder for which there is no cure.

- **Evidence Against:** I have the power to follow through with all treatment recommendations, including PT, OT, and Speech. I can participate in Ataxia research and fundraising, and learn to more effectively manage my mood.

- **Rationale Response:** I am not helpless. There are many strategies that I can use to more effectively manage my symptoms and enhance my overall quality of life. Even when I can’t control physical symptoms as much as I would like to, I can control
Cost-Benefit and Act “As If”

Cost-Benefit Analysis:
- “I can’t handle this.”

Act “As if”:
- “I am a worthwhile human being” (the opposite of “I am worthless”).
Behavioral Experiment

**Negative Thought or Prediction:**
“**Nobody** (e.g., not one person) at the party will talk to me.”

**Experiment:**
I will go to the block party on Saturday at 3 pm. I will keep track of how many people I talk to and how I spend my time.

**Outcome:**
I enjoyed getting out of the house. I said hello to 12 different people and every single one of them talked back. I had a more in-depth chat with 3 neighbors and sat amongst groups of people all afternoon, laughing with them, as they told their stories. I was
Clinical Vignette

- 64-year old married male
- 11 year history of a Movement Disorder
- Moderate motor symptoms
- Significant depression
## Summary Sheet

<table>
<thead>
<tr>
<th>Negative Thought</th>
<th>Revised Thought</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have <em>no</em> control over my symptoms.</td>
<td>There are many things I can do to manage my symptoms, even if I can’t “cure” my condition.</td>
</tr>
<tr>
<td>My neurologist thinks I am a <em>hopeless</em> case.</td>
<td>My neurologist makes very strategic treatment recommendations, as she knows there are ways I can improve my quality of life.</td>
</tr>
<tr>
<td>I have <em>nothing</em> to look forward to.</td>
<td>I can still have a meaningful life despite my symptoms.</td>
</tr>
<tr>
<td><em>Nobody</em> at the party will talk to me.</td>
<td>At least some people at the party will talk to me. It is highly unlikely that I will be completely ignored.</td>
</tr>
</tbody>
</table>
Caregiver Intervention

- **Psychoeducation:**
  - Psychiatric symptoms in Movement Disorders
  - “Red Flags”
  - Social support

- **Techniques for:**
  - Helping with “homework”
  - Supporting behavioral changes
  - Minimizing helplessness (e.g., not offering assistance when it is not needed)
  - Recognizing and responding to pessimistic thoughts
Caregiver Intervention

What might your loved one say about the meaning of this illness?

- “I’m useless.”

What might you say?

- “I still depend on you for many things. You are my confidant and my best friend. You are a terrific artist and a creative thinker. You accomplish a great deal each day, despite the difficulties that the Ataxia causes for you.”
Depression Outcomes in Movement Disorders

Hamilton Depression Rating Scale (HAM-D)

- Change from Baseline
- Time

Baseline | Midpoint | Endpoint | Follow-up

- CBT
- TAU
Depression Outcomes in Movement Disorders

Beck Depression Inventory (BDI)

Change from Baseline

Time

Baseline  Midpoint  Endpoint  Follow-up

CBT  TAU
Co-Morbid Psychiatric and Functional Outcomes

*Secondary Outcomes Improved!*

- Anxiety
- Coping - positive reframing
- Quality of Life - social functioning
- Motor Function
- Negative Thoughts
Caregiver Participation Matters!

Hamilton Depression Rating Scale

Change in Score

Time

Week 0
Week 10
Week 14

0-1 CG Sessions
2-3 CG Sessions
4 CG Sessions
Telephone-Based CBT
Conclusions

- YOUR MOOD IS ONE CRITICAL ASPECT OF YOUR MEDICAL CONDITION THAT YOU CAN CONTROL!

- DON’T SUFFER IN SILENCE!

- EFFECTIVE TREATMENTS ARE AVAILABLE!
  - Initial data regarding CBT for depression and anxiety in Movement Disorders are promising.
  - Explore telehealth approaches as needed.
Select References

Select References


